
Maintaining Confidentiality in a Look-Back Investigation of Patients Treated by a HIV-Infected Dentist

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Synopsis

The spread of human immunodeficiency virus (HIV) from a Florida dentist with acquired immunodeficiency syndrome (AIDS) to several of his patients has generated considerable concern about the risk of HIV transmission during dental treatment. Accordingly, self-reporting of HIV infection and subsequent AIDS by a dentist at our medical center prompted notification and testing of patients at risk. Key features of the notification and testing process were (a) only patients who had undergone

procedures deemed to pose appreciable risk of exposure to the dentist's blood were notified, (b) the identity of the dentist was shielded by not including in notification letters any identifying information other than the name of the medical center, and (c) patients' blood specimens were tested promptly for HIV antibodies and results were reported immediately to each patient to minimize the period of anxiety.

HIV antibody testing was requested by 41 of the 88 patients to whom notification letters were sent, and all 41 were HIV negative after having undergone 395 procedures by the HIV-infected dentist. Review of the 88 patients' medical and dental records showed that at least 77 had received treatment by other health care providers at the medical center so that they would not be able to ascertain which provider had HIV infection. None of the patients who were notified by the medical center subsequently queried the dentist concerning possible HIV infection.

Our experience demonstrates that look-back investigations can be conducted by institutions in a manner that substantially protects the identity of health care workers with HIV infection, minimizes the number of patients discomforted, and avoids excessive utilization of personnel time. Even greater protection of the identity of health care workers with HIV infection presumably can be achieved when notification is undertaken by a public health agency.

TRANSMISSION of human immunodeficiency virus (HIV) to five patients treated by a Florida dentist with acquired immunodeficiency syndrome (AIDS) (1-4) has increased concern about possible spread of HIV from infected health care workers to patients. In response to this concern, restrictions on the professional activities of some infected health care workers have been advised (5-7) and imposed (8,9). Also, look-back investigations have been conducted to learn if infection occurred in previously exposed patients who received dental, medical, or surgical treatment from HIV-infected health care workers (2,8-16). Although these investiga-

tions have not found additional instances of proven transmission of HIV to patients, look-back investigations remain an important consideration for institutions and public health agencies aware of infected health care workers who have performed what Centers for Disease Control and Prevention (CDC) term "exposure-prone invasive procedures" (6).

A critical issue in look-back investigations is the confidentiality, or right to privacy, of the infected health care worker. Although published investigations often involved practitioners who had died (11,12) or whose confidentiality was not being

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maintained in life (2,8,10,12), such people probably comprise only a small proportion of health care workers aware of their HIV infection. For other infected health care workers who might consider reporting their condition to authorities, potential benefits to society of a look-back investigation must be weighed against the person's desire to maintain privacy. Also, for institutions or public health agencies aware of HIV-infected practitioners, a perceived responsibility to notify potentially exposed patients may impinge on ethical or legal obligations to maintain the health care worker's confidentiality.

Consideration of the issues related to confidentiality was stimulated at our medical center by the knowledge that a health care worker who had performed invasive procedures had developed AIDS. With the cooperation of that health care worker, a look-back investigation was conducted in which patients deemed to be at highest risk of blood exposure were notified and offered HIV testing while the worker's identity was shielded. In this report, we describe both our findings and our approach, which may help guide other institutions that feel a responsibility to notify patients treated by HIV-infected health care workers.

Methods

Background. A dentist at our institution who learned that he or she had HIV infection promptly reported this condition voluntarily to appropriate University of Chicago Hospital (UCH) and university officials and halted routine clinical practice. Several months later, the dentist developed AIDS. When it was reported soon thereafter, in January

1991, that at least three patients of a Florida dentist with AIDS had become infected with HIV during dental treatment (2), an ad hoc committee of UCH and university officials met to consider a look-back investigation. The committee gathered preliminary information concerning the type and number of procedures performed by the institution's dentist and reached three decisions: (a) a look-back investigation was warranted to ensure patient well-being, (b) the look-back investigation should, if possible, be conducted using a hierarchy-of-risk approach by which only patients who had undergone procedures considered a priori to pose appreciable risk would be contacted initially, and (c) every effort would be made to protect the confidentiality of the HIV-infected dentist.

At the onset, peripheral blood mononuclear cells from the dentist were collected and stored at -70 degrees centigrade for subsequent HIV isolation and nucleic acid sequence typing in the event that any HIV-infected patients were found.

Hierarchy-of-risk classification. In consultation with dental experts from the institution and CDC, dental procedures coded by the American Dental Association's Council on Dental Care Programs (17) were assigned to one of five different categories based on the likelihood of injury to the dentist resulting in possible inoculation of the dentist's blood into the patient. This classification was devised by two of us (P.M.A. and R.S.), based on clinical experience and on interviews with dentists concerning injuries that occur during dental treatment. Oral surgery procedures, such as extractions, were assigned the highest risk (category V). Other categories in descending order of risk were periodontal procedures, including prophylaxis (category IV); endodontic procedures (category III); other dental procedures requiring use of a high speed burr, needle, or sharp instrument (category II); and procedures for which no needle or sharp instrument was used (category I). Procedures classed in categories III through V were considered potentially to pose appreciable risk to patients.

Review of patient records and aseptic practices. Computerized billing records for the 31-month period of the dentist's clinical practice were assembled to identify all patients treated by the dentist or by residents under the dentist's direct supervision. Dental records of these patients were sought and reviewed to identify all procedures performed by the dentist. Patients who already had HIV infection at the time of dental treatment were identified by

the dentist, and HIV infection was confirmed either by notations in the dental record or by the patient's voluntary transfer to a practice specializing in the care of HIV-infected patients. Dental and medical records of the patients on whom the dentist had performed procedures classed in categories III-V also were reviewed to determine the number of other health care workers who had provided invasive and noninvasive care during the previous 5 years. The CDC definition of invasive procedures was used (6).

The dentist was interviewed concerning routine aseptic practices and the possible occurrence of any accidents that might have exposed patients to the dentist's blood. Also, aseptic practices in the dental facility were assessed by interviews of staff members and by inspection.

Notification and testing of patients. In an effort to assure the dentist's confidentiality, discussions were held with the Illinois Department of Public Health to learn if that department could notify patients without identifying the involved institution or health care worker. As of June 1991, the department of public health was unable to undertake patient notification, so it was then decided that notification of patients would be done by the institution.

After review by the dentist's attorneys, letters signed by the Associate Dean for Clinical Affairs were sent by registered mail to the patients on whom procedures classed in categories III, IV, or V had been performed by the dentist. The letters stated that the patient had received treatment at the institution from a HIV-infected health care worker but did not disclose the worker's occupation or when treatment was rendered. The patient was encouraged to call a special telephone number to reach an administrative assistant who would arrange counseling and HIV antibody testing at no charge. Two nurses who received training specific to this situation were designated to counsel and draw blood for testing from these patients. Neither the administrative assistant nor the nurses were told the identity or profession of the HIV-infected dentist. HIV antibody testing by enzyme immunoassay was performed within 24 hours of the time each blood specimen was drawn, and the result was communicated, usually by telephone, immediately to the patient.

Approval for manuscript publication. The HIV-infected dentist considered the findings of this investigation to be important to dental and public

health professionals. Accordingly, the dentist gave permission to disclose in a scientific publication his or her occupation and diagnosis of AIDS.

Results

There were 904 patients listed on computerized billing records as having received treatment from the HIV-infected dentist or residents supervised by the dentist. Dental records were located for 845 (93 percent) of these patients, including 219 of the 224 patients billed for procedures considered potentially to pose appreciable risk (categories III-V). By complete review of the 845 dental records, 102 patients were confirmed to have had procedures in categories III-V performed by the HIV-infected dentist; dental residents supervised by the HIV-infected dentist had performed the other categories III-V procedures billed in the dentist's name. For 35 of the patients treated by the dentist, the procedure in categories III-V had not been entered on the billing record but was detected by perusal of individual dental records for this investigation. Nineteen of the 102 patients who had categories III-V procedures performed by the HIV-infected dentist were known to have had HIV infection prior to dental treatment so were excluded from further consideration.

The remaining 88 patients who underwent procedures in categories III-V were designated to be notified initially. Included were all 83 patients not previously known to be HIV-positive and on whom categories III-V procedures were confirmed by record review to have been performed by the HIV-infected dentist. The other five patients were those whose dental records could not be located but who had been billed for category III-V procedures by the HIV-infected dentist.

In July 1991, notification letters were sent to the 88 patients. Letters were accepted by 68 patients, 16 patients could not be located, and 4 had died. Three of the four who had died had continued to receive treatment at the medical center, and none had evidence of acute HIV infection, AIDS, or an AIDS-like illness. Forty-one patients underwent HIV antibody testing at the medical center, and all had negative test results. Testing was performed for all 41 patients more than 6 months after the last visit to the HIV-infected dentist.

The HIV-infected dentist performed 395 procedures on the 41 patients who were tested at the medical center. These included 11 category V procedures on 8 patients, 20 category IV procedures on 16 patients, 86 category III procedures on

26 patients, and 278 categories I or II procedures on 36 patients. One of the patients tested was among those whose dental records could not be located. This patient was billed for one category IV procedure. Based on the negative findings in this group of patients considered to be at greatest risk of dental procedure-related HIV infection, no additional patients were notified.

To learn if disclosing the name of the medical center might have enabled some of the 88 patients to ascertain the identity of the infected health care worker, the number of other health care providers at the medical center was assessed for each patient. Among the 87 patients for whom partial or complete dental and medical records were found, 76 (87 percent) had been treated by at least one health care practitioner other than the HIV-infected dentist during the 5 years before notification. The mean number of outpatient health care providers was 8.2 (median = 7), and the range was 1 to 25. In addition, 25 patients had 69 hospital admissions during which they received care from numerous health care workers. Twenty-seven patients underwent 61 invasive procedures other than those performed by the HIV-infected dentist.

The HIV-infected dentist understood the rationale for and reportedly adhered carefully to infection control procedures in the dental clinic. No accidents or breaks in aseptic technique were recognized to have occurred, and the dentist did not have dermatitis, a bleeding disorder, or neuropsychiatric impairment. Inspection of the dental clinic and review of routine aseptic practices disclosed no apparent problems in instrument sterilization, environmental cleaning, or patient care procedures. Except for dental handpieces, instruments that penetrated or came into contact with mucous membranes were sterilized in monitored autoclaves after each use. Handpieces underwent either high-level disinfection or sterilization after each use. Gloves were worn by all dental personnel for procedures in which hands may come in contact with the patient's mucosal surfaces, saliva, or blood. Other dental personnel confirmed that the HIV-infected dentist had adhered to standard aseptic practices.

Discussion

The ethical and legal issues intrinsic to look-back investigations of patients exposed to HIV-infected health care workers have been delineated (18), but no consensus has been reached concerning the circumstances which should prompt an investiga-

tion. Guidelines from CDC advise consideration of patient notification on a case-by-case basis (6). Other groups have proposed specific, and sometimes narrow, indications, for example, exposure of a patient to "blood or other hazardous body fluid" of a HIV-infected health care worker (19), or evidence of HIV transmission or a high risk of transmission due to "egregious" violations of aseptic practices (8). Look-back investigations also have been sanctioned to collect information to define better the risk of HIV transmission to patients in health care settings (6,8).

At our institution, the motivation to conduct a look-back investigation was based instead on a perceived responsibility to notify patients of a potential risk associated with treatment rendered at the institution. Although there was no indication that any patient had been inoculated with blood from the institution's HIV-infected dentist, it seemed prudent to initiate a look-back investigation, based on newly published information clearly implicating a Florida dentist in HIV transmission to patients (2). The same considerations prompted dental facilities elsewhere to notify patients treated by HIV-infected students (14,16).

An important consideration in the look-back investigation was protection of the dentist's privacy. This privacy was mandated by Illinois law (20) and was critical to the dentist's close cooperation with the investigation. Notification of patients by the institution, an approach used in other investigations (9,14-16), substantially shielded the dentist's identity. Only 11 of the 87 patients whose records could be located received treatment at the medical center solely from the dentist, and some of those patients may have had unrecorded contact with other personnel in the dental clinic. It appears that the notification process did not enable patients to identify the HIV-infected dentist or that patients did not feel vindictive toward the dentist, because the dentist received no telephone calls or letters from patients. The level of confidentiality presumably was greater than in other investigations where patients and news media were informed of the occupation (dental student) of the HIV-infected health care worker (14-16). Even greater protection of the dentist's identity could have been achieved if a public health agency had been able to undertake notification on behalf of the medical center.

For our investigation, presumed risk of HIV transmission to patients was stratified based on our perception of the likelihood of permucosal inoculation of the dentist's blood during specific dental procedures. Procedures such as extractions or scal-

ing and root planing (prophylaxis), which routinely caused the patient to bleed and which required instruments or force that might injure the dentist, were targeted in this as in one other investigation (15). The dental handpiece, which potentially could transmit infectious agents from patient-to-patient (21), was not considered a likely means of dentist-to-patient transmission. The concept of stratifying risk according to procedure emerged from studies of hepatitis B transmission by dentists (22-25) and was supported by evidence that all five HIV-infected patients of the Florida dentist had undergone procedures classed in our categories III-V (2-4).

Although imperfect, risk stratification provided a means of targeting resources at the subgroup of patients most likely to benefit from notification and post-exposure testing, and it minimized the number of patients who might be able to determine the identity of the HIV-infected health care worker. Also, the strategy of initially notifying only the patients thought to be at appreciable risk and of testing their blood within 24 hours for HIV antibodies minimized the emotional trauma a look-back investigation imposed on patients. Had transmission of HIV been detected in the highest risk subgroup of patients, the investigation then could have been expanded to include other groups of patients.

The findings of this study and others (8-16) support the view that the risk of HIV transmission to patients during invasive or other increased risk procedures generally is very low and that infection of the Florida dentist's patients represents a highly unusual situation. However, there are substantial limitations in the scope of published information that make it difficult to draw strong conclusions about the risks associated with dental treatment. First, almost all of the data from look-back investigations have been reported only in composite form by CDC (13). The CDC report does not identify the number of patients treated by dental professionals or the results of testing of that subgroup of patients. Second, the number of patients tested in fully reported, negative look-back investigations is small. Only 332 patients have been tested in this and four other published negative dental studies (9,14-16), in contrast to the approximately 1,100 patients of the Florida dentist who were tested (13). Third, in neither the previously published negative studies nor the present one did the HIV-infected dental practitioner apparently have AIDS when treating patients. Since the level of HIV in plasma and CD4+ lymphocytes increases considerably in

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advanced HIV infection (26-29), it is likely that blood from the Florida dentist with AIDS posed a greater risk. Fourth, the dental practitioners in the negative studies were working in teaching settings where attention to aseptic practices probably was greater than in the Florida dentist's private office (2).

Public concern about the risk of HIV transmission from health care workers to patients has sensationalized some cases of AIDS (12) and prompted extreme legislation such as a recent Illinois law requiring the Illinois Department of Public Health to notify patients who have undergone invasive procedures performed by a HIV-infected health care provider if there is a "potential risk" of HIV transmission (30). Additional information about the risk of HIV transmission to patients will help to inform discussions and public policy concerning this emotionally charged issue. The gathering of such information may be facilitated if HIV-infected health care workers who wish to report their condition know that their confidentiality can be maintained in any subsequent look-back investigation, and the expenditure of resources can be minimized if investigations focus on patients considered to be at greatest risk.

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